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ADJUSTMENT PERSONALITY TRAIT AND THE PROCESS OF GRIEVING
AMONG PARENTS WHO HAVE HAD CHILDREN DIE OF SIDS

A Thesis

Presented to the

Department of Counseling

and the

Faculty of the Graduate College

University of Nebraska

In Partial Fulfillment

of the Requirements for the Degree

Master of Arts

University of Nebraska at Omaha

by

Agnes Melissa Ibanez

November 2001

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THESIS ACCEPTANCE

Acceptance for the faculty of the Graduate College,
University of Nebraska, in partial fulfillment of the
Requirements for the degree Master Arts
University of Nebraska at Omaha

Committee

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Date November 9, 2001

ADJUSTMENT PERSONALITY TRAIT AND PROCESS OF GRIEVING AMONG
PARENTS WHO HAVE HAD CHILDREN DIE OF SIDS

Agnes Melissa Ibanez, MA

University of Nebraska, 2001

Advisor: Jeannette Seaberry, Ph.D.

The research examines emotional adjustment personality trait as related to intensity of grief experienced by parents who have had a child die of SIDS (Sudden Infant Death Syndrome). The NEO-Five Factor Inventory (NEO-FFI) neuroticism scale measured emotional adjustment trait, and Perinatal Grief Scale (PGS) measured grief intensity. Thirty-three participants from 18 states were recruited via SIDS Alliance and SIDS Network websites. Results supported the hypothesis that there is a direct significant correlation between emotional adjustment and grief experiences. Other results showed that grief intensity was inversely correlated with years since child's death, conscientiousness, and extraversion. Conscientiousness was found to directly correlate with years since child's death.

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CHAPTER I

Introduction

Almost always, there is intense grief associated with Sudden Infant Death Syndrome (SIDS). SIDS ranks among the three leading causes of infant mortality, being grouped with congenital anomalies and the effects of low birth weight or short gestation. (Matthews, Curtin, & MacDorman, 1998). The SIDS diagnosis is affixed postmortem when no known or possible cause for an infant's death can be found following a thorough autopsy, death scene investigation, and review of the child's medical history (American Academy of Pediatrics 2001). As many as 80 percent of the deaths due to SIDS occur prior to 5 months of age (Goyco & Beckerman, 1990).

The etiology of SIDS remains elusive, but medical research has identified two specific tissue abnormalities that are commonly found during SIDS autopsies. The first abnormality is brainstem gliosis, reflected as an increased number of star shaped cells in the brainstem (Goyco & Beckerman, 1990). The second abnormality is the presence of minute hemorrhages of the heart, lungs, and thymus, that appear as tiny red or purple spots on those organs (Krous, 1988). The specific nature of these abnormalities delineates SIDS as a distinct clinical occurrence.

Numerous factors appear to increase a child's risk for SIDS, but no factor has yet been identified as causative. Some of the risk factors relate directly to the mother and her health. These maternal risk factors include smoking cigarettes during pregnancy, maternal age of less than 20 years, poor pre-natal care, low pregnancy weight gain, anemia, use of illegal drugs and history of sexually transmitted disease or urinary tract

infection. Factors related to the infant include inadequate oxygenation of the blood (resulting in blue discoloration of skin, or a “blue baby”), tachycardia, respiratory distress, irritability, hypothermia, poor feeding, and accelerated breathing, or tachypnea.(American Academy of Pediatrics, 2001; Culbertson, Krous, & Bendell, 1988; Goyco & Beckerman, 1990).

Background/Significance of the Problem

The grief process among SIDS parents is unique because the death is sudden, unexpected and lacks a discernable cause (DeFrain, Ernst, Jakub, & Taylor, 1991). Intellectually, most SIDS parents can accept that they are not at fault, but at an emotional level they struggle with the infant’s cause of death (McKenna, 1992). Following the loss of a child through SIDS some studies have described a steady decline in the intensity of grief response over time while others have reported continued grief intensity years after the loss (Boyle, Vance, Najman & Thearle, 1996; Lang, Gottlieb, & Amsel, 1996; Potvin, Lasker, & Toedter, 1989). It is unclear what accounts for the substantial variability in parental grief in SIDS cases. A number of studies cite parents' age, gender and socioeconomic status as factors that may influence the process of grieving (Dyregov & Dyregov, 1999; Stinson & Lasker, 1992). Parkes’ (1986) study suggested that personality characteristics are factors that may contribute to the ability to cope.

Statement of the Problem

Extending the research of Parkes (1986), if personality characteristics are related to coping then differences in grief intensity experienced by a SIDS parent will vary according to emotional adjustment to daily stressors. Therefore, this study addresses the

question: Is there a relationship between emotional adjustment personality trait and the process of grieving among parents who have had a child die of SIDS?

Purpose of the Study

The purpose of this study was to determine whether high or low emotional adjustment relates significantly to the intensity of grief experienced by parents whose child(ren) have died of SIDS. The study correlated participant's survey answers to the NEO Five-Factor Inventory (NEO-FFI; Costa & McCrae, 1992) and Perinatal Grief Scale (PGS; Toedter, Lasker, & Alhadeff, 1988). The literature on neuroticism suggests a direct correlation between emotional adjustment and neuroticism (Costa & McCrae, 1992). Therefore, emotional adjustment trait was measured using the neuroticism scale of the NEO-FFI (i.e. high adjustment corresponded with low levels of neuroticism) and the differences in the process of grieving was measured according to intensity of grief reported in the PGS. The different facets measured by the PGS include active grief, difficulty coping and despair. Besides neuroticism, the NEO-FFI measures extraversion, openness, agreeableness and conscientiousness. Conclusions regarding those variables are beyond the scope of this study, but the findings are reported relative to the implications for future grief research.

The grief experience varies from person to person. It is suggested that the study can give a better understanding of personality differences that may affect the process of grieving. Furthermore it is suggested that this study may help mental health professionals decide whether grief counseling should incorporate skills building sessions (e.g. coping

skills to deal with daily stressors) to help those with low emotional adjustment personality trait.

Research Hypothesis

This study tested the hypothesis that that higher levels of neuroticism, as measured by the NEO-FFI, would correlate significantly with lower levels of emotional adjustment and higher levels of grief intensity as measured by the Perinatal Grief Scale (PGS).

Operational Definition of Terms

The following terms are defined in context of this study.

Agreeableness is one of the five personality factors measured by the NEO-FFI. The agreeable person is altruistic, sympathetic, and believes that others will be equally helpful in return. This is not considered a socially preferred or psychologically healthier trait. For example, agreeableness may not be a desired trait when a person is expected to be able to fight and defend personal interests in the courtroom. A high score in agreeableness is associated with Dependent Personality Disorder whereas, a low score is associated with Narcissistic, Antisocial, and Paranoid Personality Disorder (Costa & McCrae, 1992).

Active Grief is one of the scales measured by the PGS. Active grief is also referred to as “normal grief” experienced after the loss of a loved one. This entails current feelings of sadness, missing the loved one, and crying for the loved one (Potvin, Lasker, & Toedter, 1989).

Bereavement refers to the state of being bereaved or deprived of something (Merriam-Webster, 1997).

Conscientiousness is one of the five personality factors measured by the NEO-FFI. The conscientious person is purposeful, strong-willed and determined. This trait is associated with academic and occupational achievement. A person scoring high on the conscientiousness trait may exhibit compulsive neatness, fastidiousness, or workaholic behaviors (Costa & McCrae, 1992).

Difficulty Coping is one of the scales measured by the PGS. After the death of a loved one, a person experiencing difficulty coping may have problems in dealing with activities, and withdraw from other people. There is a high correlation between depression and difficulty coping, therefore a person that may have difficulty coping may also be experiencing severe depression (Potvin, Lasker, & Toedter, 1989).

Despair is one of the scales measured by the PGS. A person experiencing despair will have a greater potential for serious long-lasting effects because of the loss of a loved one (e.g. overall meaning of life is diminished). This intense grief reaction may indicate that the person is experiencing pathological grief (Potvin, Lasker, & Toedter, 1989).

Emotional adjustment personality trait is the ability to remain calm, even-tempered, relaxed, emotionally stable and able to face stressful situations without becoming upset or rattled. Low levels of emotional adjustment correspond to high levels of neuroticism, likewise, high levels of emotional adjustment correspond to low levels of neuroticism (Costa & McCrae, 1992).

Extraversion is one of the five personality factors measured by the NEO-FFI. The extraverted person is sociable, assertive, active and talkative. A person scoring high extraversion may prefer excitement, stimulation, and tend to have a cheerful disposition.

(Costa & McCrae, 1992). The NEO-FFI does not consider the extraversion as the opposite of introversion. Rather, introversion is seen as the absence of extraversion. Thus, introverts are seen as reserved rather than unfriendly, independent rather than followers, and preferring to be alone rather than being shy (Costa & McCrae, 1992).

Grief is an emotional distress caused by the death of a loved one (Merriam-Webster, 1997).

Mourning or “grief work” is the process of coping with loss and grief in an attempt to manage those experiences by incorporating them into everyday living (Siggins, 1966).

Neuroticism is one of the five personality factors measured by the NEO-FFI. Neuroticism generally refers to emotional instability. A person high in neuroticism may have elevated feelings of fear, sadness, embarrassment, anger, guilt and disgust. The disruptive emotions may tend to interfere with adaptation, rational thinking, inability to control impulses, and to cope more poorly compared to others. Individuals who score low in neuroticism tend to be emotionally stable, calm, even-tempered, relaxed and are able to face stressful situations without becoming upset or rattled (Costa & McCrae, 1992).

Openness is one of the five personality factors measured by the NEO-FFI. This trait relates to openness to experiences. The elements related to Openness include active imagination, aesthetic sensitivity, attentiveness to inner feelings, preference for variety, intellectual curiosity, independence of judgement, and creativity. A person low in openness tends to be conventional in behavior, conservative in outlook, preferring familiar to the novel and may have muted emotional responses (Costa & McCrae, 1992).

Assumptions

The assumptions of this study include the following: (a) the Neuroticism personality trait is stable over time, (b) participants are open and honest about their feelings of grief, and (c) some level of grief over the death of a child is still being experienced.

Limitations/Delimitations

Since the study focused on parents who have had children die a sudden death, the findings may not generalize to other parents who have children die from a prolonged illness. Another limitation of the study is the non-randomization of participants and possible effects of volunteerism on the validity of the experiment (Arnett & Rikli, 1981). In this study, participants were recruited via e-mail and website postings from the nationwide SIDS Alliance and SID Network. The researcher did not have any personal interaction with the participants. Therefore, not having met the researcher, volunteer participants may have been more or less comfortable reporting their grief. In addition, since initial recruitment was done via e-mail contact, participants had to have some level of computer literacy and have access to a computer in order to participate in the study. However, since the study was conducted via e-mail and website postings, volunteer participants were recruited across the United States with participants residing in approximately 20 different states.

Organization of Report

Chapter I explains the medical diagnosis for SIDS, the need for further studies on parental grief reactions, statement of the problem, purpose of the study, research hypothesis, operational definition of terms, assumptions, limitations, and delimitations.

Chapter II discusses the literature related to grief counseling and personality traits in coping with everyday life. Chapter III describes the methods used in this study. This includes research design, participant recruitment, procedures, instrumentation, hypothesis, data collection and analysis. Chapter IV discusses the results. Finally, Chapter V discusses the implications for future research.

Chapter II

Literature Review

Process of Grieving

Grief can be manifested in feelings, physical sensation, cognition, and behaviors (Worden, 1991). Based on the manifestations of grief, Worden (1991) postulated his theory on the tasks of mourning to serve as a guide for those helping the bereaved. The mourning process includes cognitive, affective, behavioral and valuational tasks. Cognitive tasks involve knowing the facts and gathering information. Cognitive tasks seem to be very important when the death is unexpected (as in the case of SIDS), untimely, traumatic or self inflicted. Affective tasks involve expressing one's own reaction to the death (e.g. articulating feelings). Behavioral tasks take the form of commemorative activities that preserve the memory of the dead person (e.g. funeral, planting a tree, etc.). Finally, valuational tasks involve the process of finding or making meaning out of the loss.

Researchers have identified four phases of mourning: (a) shock and numbness, (b) yearning and searching, (c) disorganization and despair and (d) re-organization (Bowlby, 1961; Parkes, 1970, 1998). These phases are said to be elements that contribute to the process of realization of the loss. Shock and numbness is an initial reaction that constitutes feelings of being dazed or detached. Yearning and searching represents an effort to return to their original place or order. Disorganization and despair are reactions to the failure to return to the things in the past. Finally, re-organization is when one finds a new way of living without the physical presence of the deceased (Parkes, 1998; Rando,

1993; Worden, 1991).

Rando's (1993) process-based theory of mourning was developed to provide guidelines for therapists to help with the process of grieving. This theory provides further knowledge on evaluating, monitoring and completing tasks (Rando, 1993; Stroebe & Schut, 1999). Rando (1993) described mourning in terms of the six "R" processes:

1. Recognize the loss and be able to acknowledge and understand the death.
2. React to the separation and be able to experience the pain of the loss.
3. Recollect and re-experience the deceased and relationship, and be able to review and realistically re-experience one's own feelings.
4. Relinquish old attachments to the deceased and old assumptive world.
5. Readjust to move adaptively without forgetting the past and be able to develop a new relationship with the deceased, adopt new ways of being in the world and form a new identity.
6. Reinvest

The dual process model proposed by Stroebe and Schut, (1999) is based on empirical evidence of coping and dynamic processes. This model emphasizes an oscillation between two complementary sets of coping processes, namely, loss oriented and restoration oriented. It is suggested that oscillation between processes is necessary for adjustment. Loss oriented coping is primarily concerned with adjusting to the loss. This process may include grief work, breaking of bonds with the deceased as well as denial and avoidance of restoration oriented changes. Coping that is restoration oriented is primarily concerned with attending to life changes, doing new things, as well as denial

and avoidance of loss oriented tasks. The model also suggests that some theoretical processes in mourning are basically focused on coping with loss itself while other processes are focused on moving forward (Stroebe & Schut, 1999).

Uncomplicated Grief

The bereavement diagnosis is used when the focus of attention is reaction to the death of a loved one. As part of their reaction to the loss, some grieving individuals report feelings of sadness, insomnia, poor appetite and weight loss. The individual considers the feelings of bereavement as “normal.” In some cases, the person may seek professional help for relief associated with symptoms such as insomnia or anorexia. The duration and expression of “normal” bereavement may vary among different cultural groups. The diagnosis of Major Depressive Disorder is not given unless the symptoms are present two months after the loss. Other symptoms associated with a diagnosis of Major Depressive Episode but are not “normal” grief reactions include 1) guilt about things other than actions taken or not taken by the survivor at the time of death; 2) thoughts of death other than he or she would be better off dead or should have died with the deceased person; 3) morbid pre-occupation with worthlessness; 4) marked psychomotor retardation; 5) prolonged and marked functional impairment; and 6) hallucinatory experiences other than thinking that he or she hears the voice of, or transiently sees the image of, the deceased person (American Psychiatric Association, 2000).

Complicated Grief Reactions

Grief is considered to be complicated when the reactions are excessive, distorted or unproductive (Demi & Miles, 1987). Worden, (1991) identified four types of complicated

grief reactions as, chronic (prolonged in duration), delayed (inhibited reaction that later resurfaces in to an excessive reaction), exaggerated (disabling in ways that may lead to the development of a phobia, or physical and psychiatric symptoms), and masked (complete absence of grief that may cause difficulty but is not recognized by the individual to be attributed to the loss). Stroebe and Schut (1999) categorize complicated grief as a “loss orientation” syndrome. Complicated grief is not only focused on loss oriented processes but there is also an absence of oscillation between loss and restoration orientation.

Gender Differences and Parental Bereavement

Traditional gender-roles in American society (e.g. expression of strong feelings is more acceptable for females but discouraged for males) may encourage different type of grief experiences between mother's and father's (Schwab, 1996). Thomas (1996) further postulates that gender differences in grieving may be a result of differences in processing information (e.g. women in general process information sequentially, while, men in general process information through the identification of patterns).

Vance and Najman (1995), interviewed 220 parents who had a child die of stillbirth, neonatal death or SIDS. The parents were interviewed, at 2 and 8 months after the loss. For both mothers and fathers, the results showed a reduction of anxiety and depressive symptoms at 8 months. However, compared to the fathers, the mothers continued to report higher levels of anxiety and depression 8 months after the death of the infant. Irizarry and Willard (1999) surveyed 61 parents who had children die of SIDS. The results showed that men reported higher levels of anxiety over another pregnancy than

did women. More women wanted another pregnancy sooner than men did.

The death of a child affects marital relationships. Spouses may be coping with loss and grief in different times and in different ways. When couples experience grief, they may not be able to support each other as they would in healthy marital relationships (Schatz, 1986; Simonds & Rothman, 1992; Staudacher, 1991). Following a child's death, Hagemeister and Rosenblat (1997) found a cessation of sexual intercourse and touching among grieving couples. Some of the partners sought extramarital affairs because they perceived that sexual intercourse with their partners had meanings related to grief (e.g. neediness and emotional unavailability). Other couples reported an intense emotional experience of grief during sexual intercourse that made them cry (Hagemeister & Rosenblat, 1997).

Grief and Coping

Kubler-Ross (1969) developed a theoretical model on the five stages in coping with dying. This model was understood to be defense mechanisms that would last for different periods and would replace each other or exist at times side by side. Kubler-Ross, (1969) further noted that different people cope in different ways.

Worden (1991) notes that personality factors play a role in abnormal grief reactions. These personality factors include one's inability to cope with emotional distress, inability to tolerate feelings of dependency, and self-concept (e.g. if one's self-concept includes being "the stronger one" in the family then it may difficult to allow for the experience of feelings that would lead to adequate resolution of a loss).

Adjustment Personality Trait / Neuroticism

Neuroticism has been negatively linked to emotional adjustment. Eysenck (1970) found that individuals with high neuroticism scores respond less adaptively and are more vulnerable to emotional distress. Ramanaiah and Detwiler (1997) surveyed 245 undergraduates (111 men and 134 women) using the NEO Personality Inventory (NEO-PI) and found that high and low satisfaction groups had significantly different personalities. The surveyed showed a negative correlation between life satisfaction and neuroticism.

Furnham and Brewin (1990) studied 100 subjects and found a negative correlation between neuroticism and happiness. The study further suggested a linear relationship indicating that personality determines happiness rather than happiness affecting the personality traits.

The level of neuroticism has been a reliable predictor of relationship outcomes (Karney & Bradbury, 1995). Studies have shown that neuroticism has been negatively correlated with high levels of marital adjustment (Buss, 1991; Geist & Gilbert, 1996; Kurdek, 1997).

Conclusion

Overall, studies on neuroticism suggest that this trait accounts for individual differences on how one copes with and relates to others. Furthermore, individual differences have also been observed with persons coping with grief. While studies have addressed individual differences in neuroticism and grief per se, current studies have not specifically explored the relationship between neuroticism and grief. Thus, the current

study attempts to determine whether neuroticism correlates with grief intensity.

CHAPTER III

Method

Participants and Design

This was a non-experimental, correlational study that involved 33 parents over the age of eighteen who had children die of SIDS. These parents were members of either the National SIDS Alliance (NSA) or SIDS Network. The study related two variables, namely, emotional adjustment trait from neuroticism scale of the NEO-Five Factor Inventory (NEO-FFI) and intensity of grief from the Perinatal Grief Scale (PGS).

Procedure

Prior to soliciting volunteers to participate in the study, the researcher submitted an Institutional Review Board application for Non-Therapeutic Research and received approval number 188-01-FB from the Institutional Review Board for the Protection of Human Subjects, University of Nebraska Medical Center (see Appendix A). The primary investigator solicited the volunteers by e-mailing NSA and SIDS Alliance, requesting participants. Volunteers who were interested in taking part in the research responded via e-mail to the primary investigator. In response, the primary investigator e-mailed the volunteers requesting a mailing address. Participants were then mailed a survey packet consisting of the following: cover letter, consent form, *Your Rights as a Research Participant*, demographic information request form, NEO-FFI, PGS and a self addressed stamped envelope to return completed forms to the primary investigator (see Appendix B for cover letter, consent form, *Your Rights as a Research Participant*, and demographic information request form).

Instrumentation

The research survey packets included the NEO-FFI, the PGS, and a form for demographic information. The requested demographic information included participant's age, gender, marital status, ethnicity, education level, total number of children, birth order of SIDS infant, and SIDS infant's date of birth and death.

The NEO-FFI is a 60-item questionnaire measuring five dimensions of normal personality (i.e., neuroticism, extraversion, openness, agreeableness, and conscientiousness). Respondents rate the extent to which each statement corresponds to their self-perception on a 5-point Likert scale (1 = strongly disagree, 5 = strongly agree). It takes approximately 10 to 15 minutes for participants to complete the NEO-FFI (Costa & McCrae, 1992).

The scales of the NEO-FFI measure traits that approximate the normal, bell shaped distributions (mean = 19.07, $SD = 7.68$). Specific reliability scores for the NEO-FFI are reported for neuroticism at .79, extraversion at .79, openness at .80, agreeableness at .75 and conscientiousness at .83. Internal consistencies are reported for neuroticism at .86, extraversion at .77, openness at .73, agreeableness at .68 and conscientiousness at .81. The NEO-FFI scales have been found to correlate with analogous scales from the Self-Directed Search, Meyers-Briggs Type Indicator, Personality Research Form and Minnesota Multiphasic Inventory (Costa, Busch, Zonderman & McCrae, 1986; Costa & McCrae, 1992; McDonald, Anderson, Tsagarakis, & Holland, 1994).

The PGS is used to measure grief resulting from a miscarriage, loss of a newborn, or infant. It is a 33-item questionnaire with 3 subscales measuring: active grief, difficulty

coping, and despair. PGS reliability scores are reported for active grief at .92, difficulty coping at .91, despair at .86 and total reliability score at .95. Internal consistencies are reported for active grief at .53, difficulty coping at .48, despair at .38 and total score at .40. The intercorrelation among subscales is relatively high. The lowest correlation is between active grief and despair (.56) and the highest is between difficulty coping and despair (.80). Overall, computations suggest that each subscale gives a consistent and reliable estimate of the concept it purports to measure, measured and that these concepts are related (Toedter, Lasker, & Alhadeff, 1988). The respondents rate the extent of their present thoughts and feelings about their losses on a 5-point Likert scale (1 = strongly disagree, 5 = strongly agree). It takes approximately 5 to 10 minutes for participants to complete the PGS (Toedter, Lasker, & Alhadeff, 1988).

Data Collection/Data Analysis

This study tested the hypothesis that there is a significant correlation between high levels of neuroticism and high intensity of grief among adult parents who have had children die of SIDS. To test the hypothesis, the data were analyzed using the Pearson's Product Moment Correlation (Pearson r) computing the degree of correlation between NEO-FFI neuroticism scores and overall PGS score. An alpha level of .05 was used for all statistical computations. Measures of central tendency (mean and mode) and frequency computations (i.e. percentages) were used to describe demographic information. Further computations correlated the demographic information by assigning numerical data in place of nominal data (e.g. male = 0 and female = 1). Frequency distributions were computed for neuroticism to determine the degree to which the scores

approximated a normal distribution. The Cronbach's alpha was used to compute for inter-item reliability within the NEO-FFI and PGS.

Finally, the Pearson r correlation coefficient was calculated between demographic information, PGS and all other scales of the NEO-FFI (extraversion, openness, agreeableness and conscientiousness). The statistical analysis between demographic information, PGS and NEO-FFI outlines an indication for future research on the topic.

CHAPTER IV

Results

The purpose of this study was to investigate the correlation between neuroticism and intensity of grief among adult parents who have had children die of SIDS. The participants were contacted via website of the National SIDS Alliance and SIDS Network. Volunteer participants were mailed a demographic questionnaire, NEO-Five Factor Inventory (NEO-FFI) and Perinatal Grief Scale (PGS). The scores on the NEO-FFI neuroticism scale were correlated with PGS scores on active grief, difficulty coping, despair and total grief to determine the relationship between neuroticism and intensity of grief.

Frequency distributions were computed for the demographic information and neuroticism to describe the sample population. Cronbach's alpha was used to compute for reliability coefficients of the neuroticism and PGS scores. The Pearson Product Moment Correlation (Pearson r) was used to determine the correlation between demographic information, PGS and neuroticism scores. Additionally, the Pearson r was calculated between the remaining NEO-FFI scales (extraversion, openness, agreeableness, and conscientiousness), demographic information, and PGS.

Demographics

Of the 45 participants who received the mailers, 33 returned their completed forms. The 33 respondents resided in 18 different states (California, Connecticut, Florida, Idaho, Indiana, Maine, Maryland, Mississippi, Montana, Nebraska, New Hampshire, North Carolina, Oklahoma, Pennsylvania, South Carolina, South Dakota, Tennessee, and

Of the 45 participants who received the mailers, 33 returned their completed forms. The 33 respondents resided in 18 different states (California, Connecticut, Florida, Idaho, Indiana, Maine, Maryland, Mississippi, Montana, Nebraska, New Hampshire, North Carolina, Oklahoma, Pennsylvania, South Carolina, South Dakota, Tennessee, and Washington State). There were 28 females and 5 males. Wives of all male subjects participated in the study. This accounts for the five married couples that were included among the respondents.

The age of the respondents ranged from 21 to 60 (mean = 34.89 and mode = 31). At the time of the research, 81.8% were married, 15.2% were divorced and 3% were single. Among the participants 90.9% were Caucasian, 3% Asian, 3% Native American, and 3% Other. The level of education of the participants ranged from high school or GED (27.3%), Associate Degree or Some College (39.4%), Bachelor's Degree (27.3%) and Master's or Doctorate Degree (6.1%). The parent's age was computed at the infant's birth, and female participants' ages ranged from 14 to 38 (mean = 27.6 and mode = 25), while, male participants' ages ranged from 24 to 46 (mean = 35 and mode = 32).

The infant deaths occurred between 1964 to 2001 (mean = 1995 and mode = 2000). During the time that the research was conducted (from June to August, 2001), 15.2% of the infants were the only child. The infant's birth order ranged from firstborn to fourth born with percentage distributions as follows: 42.4% were firstborn, 36.4% were second children, 18.2% were third children and 3% were fourth children.

Neuroticism

Frequency distribution scores were computed to compare participants' neuroticism

scores with the general population (mean = 26.1, $SD = 9.67$). Figure 1, illustrates a slightly negative skewed ($-.15$) histogram. The overall scores indicate higher neuroticism scores compared with the reported NEO-FFI distribution (mean = 19.07, $SD = 7.68$). The overall scores indicate higher neuroticism scores compared with the reported NEO-FFI distribution (mean = 19.07, $SD = 7.68$). The NEO-FFI frequency distribution suggest that the SIDS parents were slightly higher in the neuroticism trait than general population.

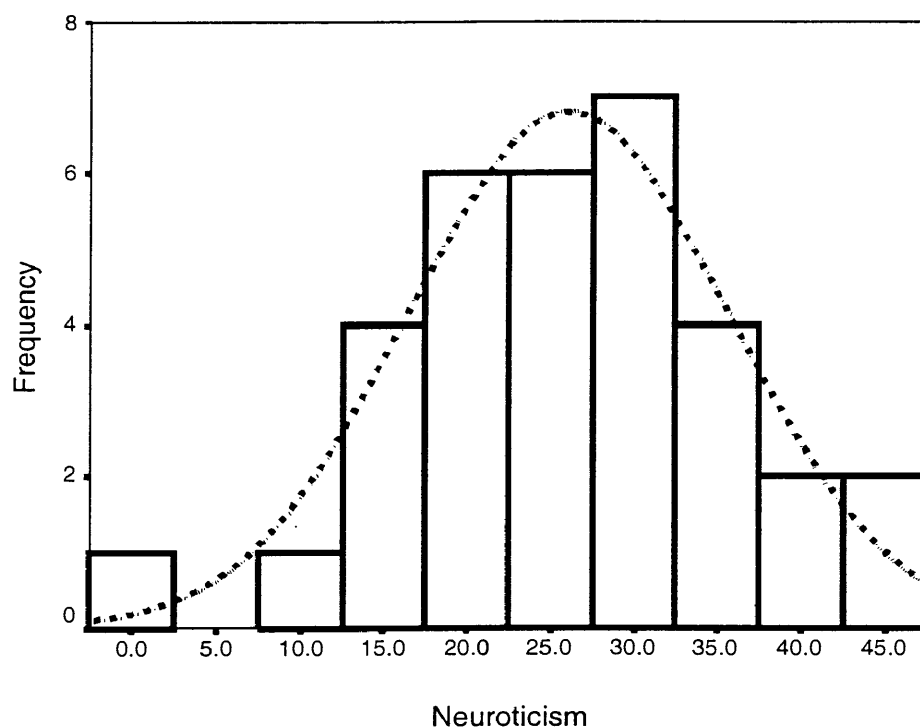


FIGURE 1

Frequency Distributions of the Neuroticism Scores

The NEO-FFI reliability coefficients were computed using the Cronbach's alpha. The NEO-FFI inter-item ratings yielded a score of .90, compared to .79 in the reference group reported by Costa and McCrae (1992). This study supports high internal consistency of the neuroticism scale. The high internal consistency suggests that items in the neuroticism scale were closely related.

PGS Reliability

Inter-item reliability coefficients were measured using Cronbach's alpha on the total PGS score and subscales (active grief, difficulty coping, and despair). The alphas for active grief, difficulty coping, despair and total PGS were .92, .93, .88, and .96 respectively. Except for the active grief score (which was equal to the reported score), the current scores were slightly higher than the reported PGS reliability scores (.92, .91, .86, and .95). These coefficients indicate high levels of internal consistency on active grief, difficulty coping, despair and total PGS. The high levels of internal consistency suggest that items within and between active grief, difficulty coping, despair and total PGS scales are closely related to each other. The Pearson r was used with the PGS subscales to correlate active grief, difficulty coping, despair and total PGS. Significant and direct correlations were found between subscales: (a) active grief and difficulty coping, suggesting that the higher the active grief, the higher the difficulty coping ($r(0) = .83, p < .05$); (b) active grief and despair, suggesting that the higher the active grief the higher the despair ($r(0) = .84, p < .05$); and (c) difficulty coping and despair, suggesting that the higher the difficulty coping the higher the despair ($r(0) = .89, p < .05$). The statistical

analysis supports previous studies that concluded that the PGS subscales were significantly correlated.

Correlation between NEO-FFI and PGS

The hypothesis proposed a significant correlation between the participants reporting high levels of neuroticism and high intensity of grief was analyzed using the Pearson's Product Moment Correlation. Using a two-tailed test, a significant direct correlation was found between neuroticism and active grief ($r(0) = .68, p < 0.05$), difficulty coping ($r(0) = .68, p < 0.05$), despair ($r(0) = .65, p < 0.05$), and total PGS ($r(0) = .70, p < 0.05$). This suggests that low levels of emotional adjustment are significantly correlated with high intensity of grief reported. Figure 2 illustrates a scatterplot between neuroticism and active grief. Figure 3 illustrates a scatterplot between neuroticism and difficulty coping. Figure 4 illustrates a scatterplot between neuroticism and despair. Finally, Figure 5 illustrates a scatterplot between neuroticism and total PGS.

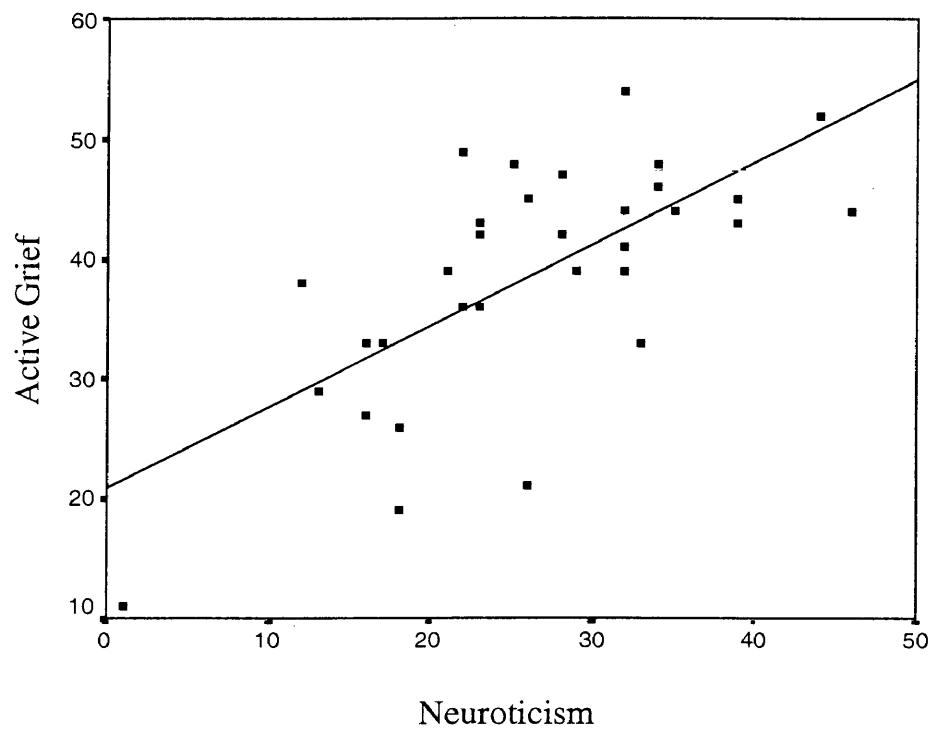


FIGURE 2

Plotted Scores Between Neuroticism and Active Grief

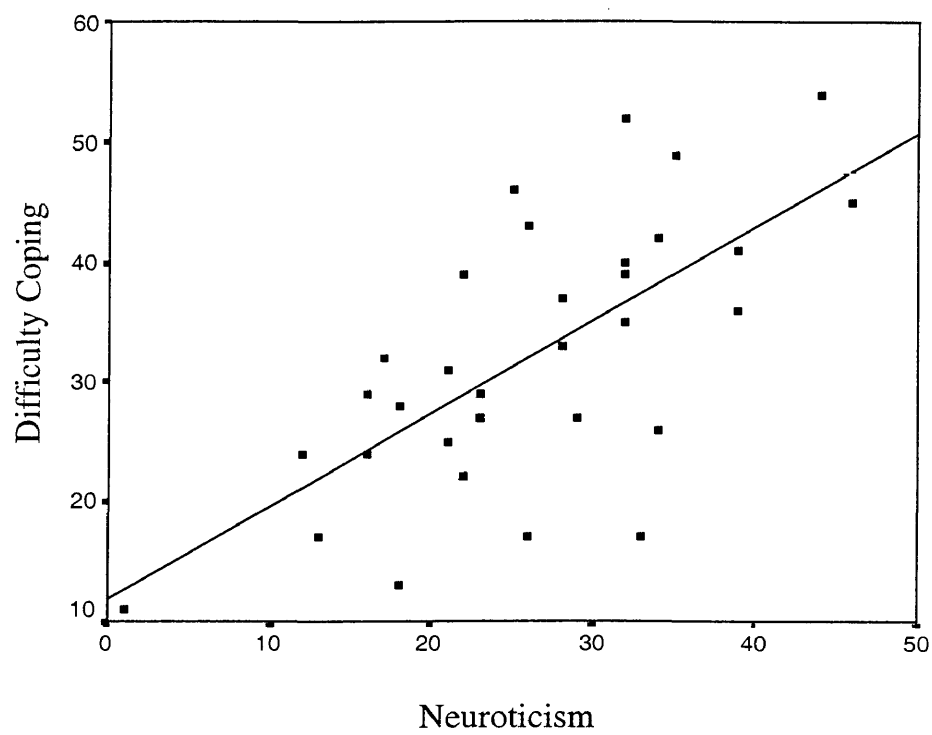


FIGURE 3

Plotted Scores Between Neuroticism and Difficulty Coping

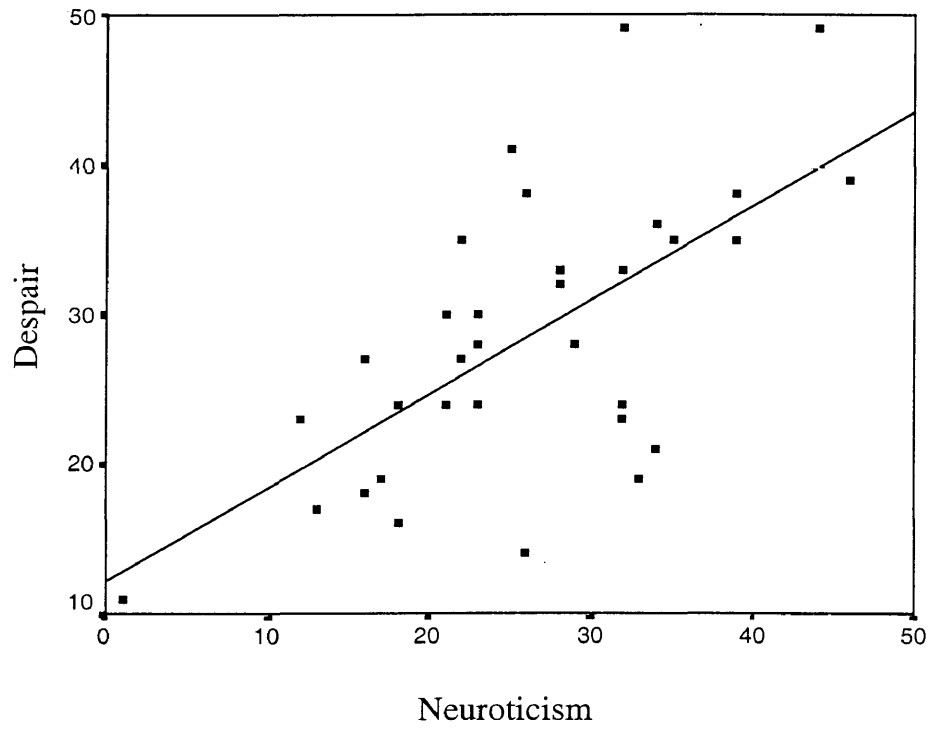


FIGURE 4

Plotted Scores Between Neuroticism and Despair

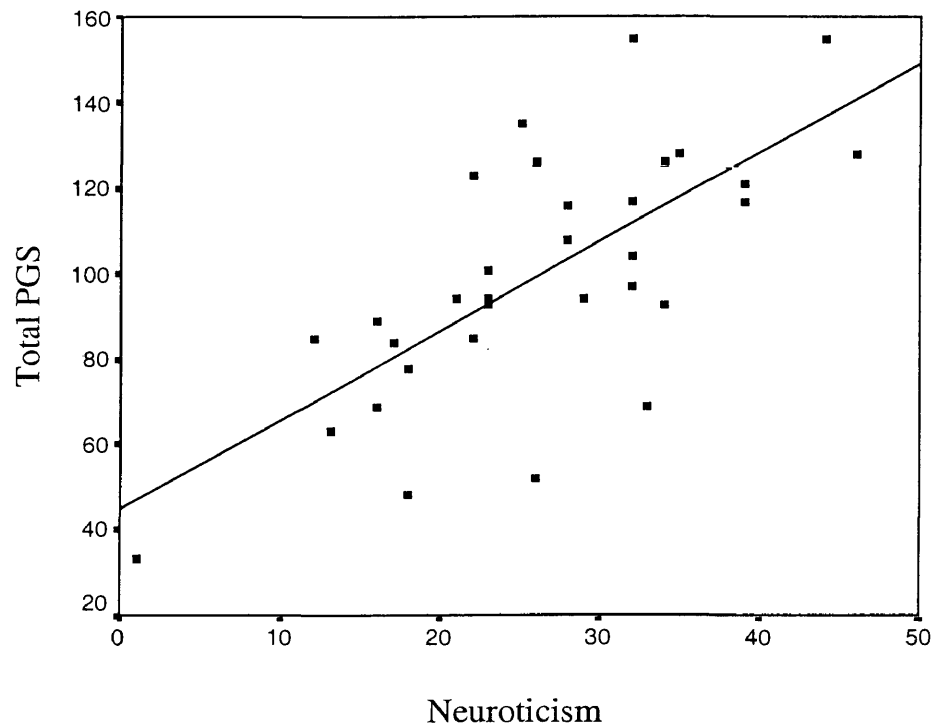


FIGURE 5

Plotted Scores Between Neuroticism and Total PGS

Further tests were conducted to correlate extraversion, openness, agreeableness conscientiousness and PGS. Using a two-tailed test, a significant inverse correlation was found between extraversion and the following constructs: (a) extraversion and active grief, suggesting that the higher the extraversion the lower the experienced grief ($r = -.093$, $p < 0.05$); (b) extraversion and difficulty coping, suggesting that the higher the extraversion the lower the difficulty coping ($r = -.039$, $p < 0.05$); (c) extraversion and despair, suggesting that the higher the extraversion the lower the despair ($r = -.007$, $p < 0.05$).

-.46, $p < 0.05$); and (d) extraversion and total PGS, suggesting that the higher the extraversion the lower the overall grief experienced ($r (.025) = -.39$, $p < 0.05$). A significant inverse correlation was found between conscientiousness and difficulty coping ($r (.004) = -.48$, $p < 0.05$), despair ($r (.005) = -.48$, $p < 0.05$) and total PGS ($r (.009) = -.45$, $p < 0.05$), but not with active grief. The correlation between conscientiousness and PGS subscales suggests that the higher the conscientiousness the lower the difficulty coping, despair and overall grief. There were no significant correlations found between openness, agreeableness and PGS. Table 1 presents a summary of the correlation between NEO-FFI and PGS.

TABLE 1
Correlations Between NEO-FFI and PGS.

	PGS			
	Active	Difficulty		Total
NEO-FFI	Grief	Coping	Despair	PGS
Neuroticism	.68*	.68*	.65*	.70*
Extraversion	-.30	-.36*	-.46*	-.39*
Openness	-.25	-.26	-.16	-.23
Agreeableness	-.26	-.24	-.19	-.24
Conscientiousness	-.32	-.48*	-.48*	-.45*

*Correlation is significant at the .05 level (two-tailed).

Correlation between NEO-FFI and demographics

Neuroticism was found to be significantly and inversely correlated with parent's age ($r(0) = -.59, p < 0.05$) and level of education ($r(.001) = -.54, p < 0.05$). The results suggest that the higher neuroticism, the younger the parents and less years of education. While conscientiousness was found to be significantly and directly correlated with years since child's death, suggesting that the higher the level of conscientiousness the more years has passed since the child's death ($r(.035) = .37, p < 0.05$). Table 2 presents a summary of correlations between NEO-FFI and demographics.

TABLE 2
Correlations Between NEO-FFI and Demographics.

NEO-FFI	Demographics		
	level of education	parent's age	years since child's death
Neuroticism	-.54*	-.59*	----
Extraversion	----	----	----
Openness	----	----	----
Agreeableness	----	----	----
Conscientiousness	----	----	.37*

*Correlation is significant at the .05 level (two-tailed).

Correlation between PGS and demographics

Using the Pearson r , the PGS subscales (active grief, difficulty coping, despair and total PGS) were correlated with the demographic information. A significant inverse correlation was found between active grief and level of education ($r(0) = -.69, p < 0.05$) while a significant direct correlation was found between active grief and years since child's death ($r(.003) = .50, p < 0.05$). The correlation between active grief and education suggests that the higher the active grief the less the years of education. While the correlation between active grief and years since child's death suggests that the higher the active grief the fewer years have passed since the child's death. Difficulty coping was found to be inversely and significantly correlated with level of education ($r(.002) = -.52, p < 0.05$) and years since child's death ($r(.006) = -.467, p < 0.05$). The correlations between difficulty coping and demographic information suggests that the higher the difficulty coping the less years of education and the less years have passed since the child's death. Despair was found to inversely and significantly correlate with years since child's death ($r(.013) = -.43, p < 0.05$), parent's age ($r(.005) = -.48, p < 0.05$), and level of education ($r(.002) = -.52, p < 0.05$). The correlation between despair and demographics suggest that the higher the despair the less years that have passed since the child's death, the younger the parents and the less years of education. Finally, total PGS scores were found to inversely and significantly correlate with parent's age ($r(.001) = -.53, p < 0.05$), level of education ($r(0) = -.60, p < 0.05$) and years since child's death ($r(.004) = -.49, p < 0.05$). The correlation between total PGS and demographic information suggest that the higher the intensity of grief: (a) the younger the parents, (b) less years of

education, and (c) less years passed since the child's death. Table 3 presents a summary of correlation between PGS and demographics.

TABLE 3
Correlations Between PGS and Demographics.

PGS	Demographics		
	level of education	parent's age	years since child's death
Active Grief	-.69*	----	-.50*
Difficulty Coping	-.52*	----	----
Despair	-.52*	-.48*	-.43*

*Correlation is significant at the .05 level (two-tailed).

CHAPTER V

Discussion

This study investigated the correlation between neuroticism and intensity of grief experienced by adult parents who have had children die of SIDS. The scores on the NEO-Five Factor Inventory (NEO-FFI) neuroticism scale was correlated with Perinatal Grief Scale (PGS) scores on active grief, difficulty coping, despair and total grief to determine whether a relationship exists between neuroticism and intensity of grief. Results indicated a direct correlation between neuroticism and PGS subscales on active grief, difficulty coping, despair and total PGS. This suggests that parents who scored high in neuroticism scale reported higher levels of grief compared to those parents that scored low in the neuroticism scale. Costa and McCrae (1992) suggested that the NEO-FFI neuroticism scale was an indicator of one's ability to cope (i.e. high neuroticism scores indicated low levels of emotional adjustment). Therefore the results suggest that when faced with loss, a person who has difficulty with emotional adjustment to daily stressors would more likely be experiencing intense grief than a person who is able to emotionally cope with everyday living.

The results suggest that the frequency of neuroticism among the obtained sample of SIDS parents were slightly elevated compared to the general population. It is possible that due to the trauma of losing a child, the parents may be experiencing some complicated grief reactions. The study did not assess whether the participants were experiencing abnormal grief reactions. Worden (1991) has suggested that abnormal grief reactions are related to one's inability to cope with emotional distress, inability to tolerate

feelings of dependency, and self-concept (e.g. perceived role in the family). Further studies are needed to determine whether the neuroticism scale could be used to identify abnormal grief reactions.

Overall E-mail Response and Recruitment

Volunteer participants were recruited via e-mail to the National SIDS Alliance and the SIDS Network. Forty-five questionnaires were mailed out to volunteer participants during the first month that the e-mail request was made. Since contact was by e-mail, some volunteer participants called the University to verify that the study was valid. The participant return rate was a high 73%. Several of the volunteer participants e-mailed the researcher to relate their experiences with SIDS. Some of the participants included photos and narrative stories. Overall, the participant recruitment was very positive and volunteers expressed their support by volunteering to help the researcher in other ways if needed.

Demographics, NEO-FFI, and PGS

Correlations were computed between demographics, NEO-FFI scales (neuroticism, extraversion, openness, agreeableness and conscientiousness) and PGS subscales (active grief, difficulty coping and despair). Significant correlations were found between: (a) grief, neuroticism, time, age and education; (b) extraversion and grief; (c) grief and conscientiousness; and (d) conscientiousness, agreeableness and years since child's death.

Grief, Neuroticism, Time, Age and Education.

The findings of this study are consistent with previous research suggesting that the

intensity of grief and neuroticism decreases over time (Costa & McCrae, 1992; Potvin, Lasker, & Toedter, 1989). This may suggest that the passage of time plays a role in the process of grief and healthy coping. The results further suggest that neuroticism and grief were related to age and education. The correlation suggests that the lower the levels of neuroticism and grief the older and the more educated were the participants. It is possible that grief reduction and healthy coping is a learned behavior that is facilitated over time. Future research may focus on life experiences that may contribute to better coping and to identify whether these healthier coping skills could be learned in an educational or clinical setting. The results in this study have shown that the higher the level education the lesser intensity of the grief. Although, the study failed to identify the participant's field of studies (e.g. number of psychology majors versus accounting majors), future studies could focus on whether the level of education and type of education is a factor that influences the process of grieving.

Grief and Extraversion.

A significant relationship was found between grief and extraversion. The results suggested that the higher the level of extraversion the lower the intensity of the grief experienced. The extraverted person is described as sociable, assertive, active and talkative (Costa & McCrae, 1992). The results support studies suggesting that extraversion is correlated to higher levels of adjustment and happiness (Brebner, Donaldson, Kirby & Ward, 1995; Diener, 1984). Thus, it suggested that level of extraversion could be a predictor of grief intensity. Worden (1991) suggested that grief is

a social process and social factors (i.e. a situation where people can support and reinforce each other in their reactions to the loss vs. absence of social support) play a role in complicated grief reactions. The participants in this study were recruited from a social support network (NSA and SIDS network) and it is possible that parents scoring high in extraversion found ways of dealing with their grief through connecting with others and building a support system with those who have similar experiences. However, Duckitt (1984) suggested that under conditions of high social support, extraverts report less distress than introverts and under condition of low social support, extraverts report greater distress than do introverts. It is possible that grief intensity is higher among those who scored low in extraversion because their needs are not being met through the social support network. Further studies are needed to determine if intensity of grieving is associated with extraversion or introversion.

Grief, Conscientiousness and Years Since Child's Death.

The conscientious person is purposeful, strong-willed and determined (Costa & McCrae, 1992). Results of the study suggested that the higher score on conscientiousness, the lower the grief intensity. Further studies are needed to determine whether conscientiousness may be a factor that contributes to the grief intensity. Other results suggested a relationship between conscientiousness and years since child's death. The results indicate that the longer length of time since the child's death the higher the reported level of conscientiousness. Costa and McCrae (1992) suggests that older individuals score higher in conscientiousness than younger individuals. It is possible that levels of conscientiousness are not factors that contribute to grief intensity. However, it is

also possible that conscientiousness could be a learned response to a traumatic event (i.e. death of a child). Further studies are needed to determine whether increased conscientiousness is a response to a loss of a child.

Implications

Given that intensity of grief is related to emotional adjustment to daily stressors, it is suggested that grief counseling incorporate skills building sessions for those experiencing unhealthy coping patterns. The skills building sessions may not necessarily relate to the loss, but to broader issues of coping with everyday living. For example, Dialectical Behavioral Therapy (DBT) skills that increase distress tolerance and emotional regulation have been shown to be effective coping skills (Linehan, 1993). Stroebe and Schut (1999) suggest that oscillation between loss and restoration oriented processes is needed in order to cope with grief. Further studies are needed to identify coping skills that would facilitate oscillation between those processes. In general, research is still needed to identify unhealthy patterns that contribute to intensity of grief and to identifying skills that would help in the process of grieving. In addition, since the present study focused on the relationship between adjustment and grief, future studies may focus on identifying possible cause and effect between variables (i.e. investigate whether unhealthy coping styles are the cause of intense grief experiences).

Conclusion

The study focused on the intensity of grief and adjustment among parents who have had children die of SIDS. The grief experienced by the parents is unique because the infant's death is sudden and no specific explanation could be given on the cause death.

The study suggests that neuroticism plays a role in the process and intensity of grieving. Thus, it may be important for those helping the bereaved to be aware of personality factors (i.e. neuroticism) that may intensify the grieving process. The study did not distinguish gender differences among the parents. Future studies are needed to determine whether there are gender differences in grief intensity and if neuroticism is related to grief intensity among other bereaved individuals.

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APPENDICES

Appendix A

IRB Approval Letter

May 31, 2001

Agnes Ibanez
Community Counseling Dept
UNO - VIA COURIER

IRB # 188-01-FB

TITLE OF PROPOSAL: Adjustment Personality Trait and Process of Grieving Among Parents Who Have Had Children Die of SIDS

SECONDARY INVESTIGATORS:

DATE OF FULL BOARD REVIEW 05-17-01 **DATE OF EXPEDITED REVIEW** _____

DATE OF FINAL APPROVAL 05-31-01 **VALID UNTIL** 05-17-02

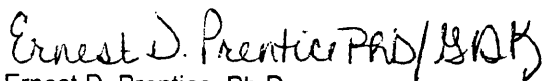
The Institutional Review Board (IRB) for the Protection of Human Subjects has completed its review of the above-titled protocol and informed consent document(s), including any revised material submitted in response to the IRB's review. The Board has expressed it as their opinion that you are in compliance with HHS Regulations (45 CFR 46) and applicable FDA Regulations (21 CFR 50.56) and you have provided adequate safeguards for protecting the rights and welfare of the subjects to be involved in this study. The IRB has, therefore, granted unconditional approval of your research project. This letter constitutes official notification of the final approval and release of your project by the IRB, and you are authorized to implement this study as of the above date of final approval.

Please be advised that only the IRB approved and stamped consent/assent form can be used to make copies to enroll subjects. Also, at the time of consent all subjects/representatives must be given a copy of the rights of research participants.

The IRB wishes to remind you that the PI or Co-PI, is responsible for ensuring that ethically and legally effective informed consent has been obtained from all research subjects. For protocols posing greater than minimal risk, the PI/Co-PI must counter sign and date all consent forms where they are not the individual obtaining and documenting informed consent. This countersignature should occur as soon as possible, but at least within 10 business days of the time the subject/representative signs the consent form.

Finally, under the provisions of this institution's Multiple Project Assurance (MPA #1509), the PI/Co-PI is directly responsible for submitting to the IRB any proposed change in the research or the consent document(s). In addition, any unanticipated adverse events involving risk to the subject or others must be promptly reported to the IRB. This project is subject to periodic review and surveillance by the IRB and, as part of their surveillance, the IRB may request periodic reports of progress and results. For projects which continue beyond one year, it is the responsibility of the principal investigator to initiate a request to the IRB for continuing review and update of the research project.

Sincerely,


Ernest D. Prentice, Ph.D.
Co-Chair, IRB

EDP/gdk

Appendix B

Cover Letter

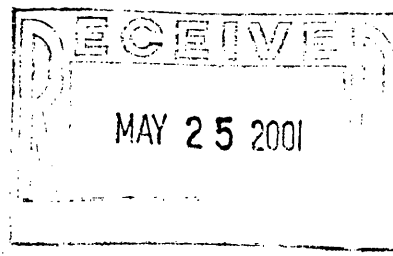
Consent Form

The Rights of Research Participants

Demographic Information



University of
Nebraska at
Omaha



College of Education
Counseling Department
Omaha, Nebraska 68182-0167
(402) 554-2727

IRB: 188-01-FB

**Adjustment Personality Trait and Process of Grieving
Among Parents who have had Children Die of SIDS**

June 2001

Dear Participant,

Thank you for your interest on the research study. Enclosed you will find the following materials: 2 Adult Consent Forms (one printed in blue and the other in white paper), Your Rights as a Research Participant, Demographic Information Sheet, NEO Five-Factor Inventory, Perinatal Grief Scale, and self addressed stamped envelope.

All blue papers, Adult Consent Form, Right as a Research Participant, and this letter are your copies. The NEO Five-Factor Inventory, and all forms printed on white paper, Consent Form, Demographic Information Sheet and Perinatal Grief Scale are to be mailed upon completion using the self addressed stamped envelope.

Please read all the forms carefully. All pages of the Consent Form need to be initialed, and last page has to be signed and dated. You may notice that some parts of the demographic information sheet are optional. You do not need to complete this portion. However, if I get a number of people to fill out this information, I may use the information for further statistical analysis.

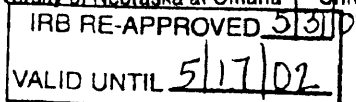
You may experience some memory discomfort from recalling the death of a child from SIDS. I urge you to use resources that may be available to you through SIDS Alliance and SIDS Network.

Should you decide not to participate, I ask that you please mail back all materials. This is to reduce costs since I am working on a very limited budget.

Thank you once again for the time in effort that you put into this study. The summary results of the study will be accessible via worldwide web at: <http://sidsstudy.freehomepage.com>. If you have any questions, please feel to e-mail me at agibanez@navix.net or call me at (402) 343-0258.

Sincerely yours,


Agnes Melissa Ibanez
Graduate Student



IRB # 188-01-FB

ADULT CONSENT FORM

ADJUSTMENT PERSONALITY TRAIT AND PROCESS OF GRIEVING AMONG PARENTS WHO HAVE HAD CHILDREN DIE OF SIDS

INVITATION

You are invited to participate in this research study. The information in this consent form is provided to help you decide whether to participate. If you have any questions, please do not hesitate to ask.

WHY ARE YOU ELIGIBLE?

You are eligible to participate because you are a member of the Nationwide SIDS Alliance or SIDS Network and have experienced a loss of an infant to SIDS.

WHAT IS THE PURPOSE OF THIS STUDY?

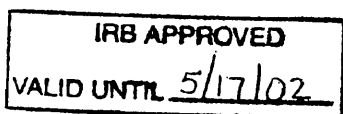
The purpose of the study is to determine whether overall high or low emotional adjustment is related to the intensity of grief experienced. The results of the study will be used to help mental health professionals evaluate whether grief counseling will be more effective with added skills building sessions.

WHAT DOES THIS STUDY INVOLVE?

Volunteers interested in participating in the research will be asked to respond to the website advertisement-posting by e-mail. The researcher will then contact the subjects via e-mail requesting their mailing address. They will be mailed a survey packet consisting of: cover letter, Adult Consent Form, Your Rights as a Research Participant, Demographic Information Sheet, NEO-Five Factor Personality Inventory, Perinatal Grief Scale and a self addressed stamped envelope. The self-stamped envelope will be used to return completed forms to the primary investigator.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS YOU COULD EXPERIENCE?

Possible risks and discomforts you could experience during this study include some discomfort from recalling the death of a child from SIDS.



_____ Participant's Initials

WHAT ARE THE POSSIBLE BENEFITS TO YOU?

The study will not have any direct benefits to you.

WHAT ARE THE POSSIBLE BENEFITS TO SOCIETY?

The study is geared to help mental health professionals understand the role of the adjustment personality trait and process of grieving. Information from this study may help to determine if grief counseling should incorporate skills building sessions to help those with low adjustment personality traits.

WHAT SHOULD YOU DO IN CASE OF AN EMERGENCY?

If you have a research concern or problem, you should immediately contact the personnel listed at the end of this consent form.

HOW WILL YOUR CONFIDENTIALITY BE PROTECTED?

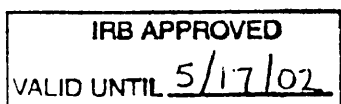
The only persons who will have access to your research records are the study personnel, the Institutional Review Board (IRB), and any other person or agency required by law. The information from this study may be published in scientific journals or presented at scientific meetings but your identity will be kept strictly confidential.

WHAT ARE YOUR RIGHTS AS A RESEARCH PARTICIPANT?

You have rights as a research participant. These rights are explained in *The Rights of Research Participants* which you have been given. If you have any questions concerning your rights, you may contact the Institutional Review Board (IRB), telephone (402) 559-6463.

WHAT WILL HAPPEN IF YOU DECIDE NOT TO PARTICIPATE?

You can decide not to participate in this study or you can withdraw from this study at any time. Your decision will not affect your care or your relationship with the investigator, or the University of Nebraska at Omaha.



_____ Participant's Initials

DOCUMENTATION OF INFORMED CONSENT

YOU ARE VOLUNTARILY MAKING A DECISION WHETHER TO PARTICIPATE IN THIS RESEARCH. YOUR SIGNATURE MEANS THAT YOU HAVE READ AND UNDERSTOOD THE INFORMATION PRESENTED AND DECIDED TO PARTICIPATE. YOUR SIGNATURE ALSO MEANS THAT THE INFORMATION ON THIS CONSENT FORM HAS BEEN FULLY EXPLAINED TO YOU AND ALL YOUR QUESTIONS HAVE BEEN ANSWERED TO YOUR SATISFACTION. IF YOU THINK OF ANY ADDITIONAL QUESTIONS DURING THE STUDY, YOU SHOULD CONTACT THE INVESTIGATOR(S). YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM.

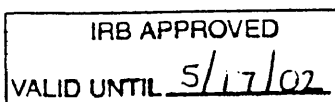
SIGNATURE OF PARTICIPANT_____
DATE

I CERTIFY THAT ALL THE ELEMENTS OF INFORMED CONSENT DESCRIBED ON THIS CONSENT FORM HAVE BEEN EXPLAINED FULLY TO THE PARTICIPANT. IN MY JUDGEMENT, THE PARTICIPANT IS VOLUNTARILY AND KNOWINGLY GIVING INFORMED CONSENT AND POSSESSES THE LEGAL CAPACITY TO GIVE INFORMED CONSENT TO PARTICIPATE IN THIS RESEARCH.

SIGNATURE OF INVESTIGATOR_____
DATE**AUTHORIZED STUDY PERSONNEL**

Principal Investigator: Agnes Melissa Ibanez, MA Candidate

phone:(402)343-0258



THE RIGHTS OF RESEARCH PARTICIPANTS

AS A RESEARCH PARTICIPANT AT THIS INSTITUTION YOU HAVE THE RIGHT . . .

. . . to be fully informed about the research before you are asked to decide whether or not to participate. This means that all information which you will need in order to make a decision will be provided to you. The information will be explained to you in a way which ensures that you have an adequate understanding of the research.

. . . to make your decision whether or not to participate in research without coercion, undue influence, or duress.

. . . to decide not to participate in this research or withdraw from participation at any time without affecting your relationship with the investigator(s), the University of Nebraska or the Nebraska Health System (NHS).

. . . to participate in research where your safety and welfare will always come first. The investigator(s) will display the highest possible degree of skill and care throughout this research. Any anticipated risks or discomforts will be minimized whenever possible.

. . . to be treated with dignity and respect at all times.

. . . to privacy and confidentiality. The investigator(s) will safeguard the confidentiality of research data to prevent the disclosure of your identity to non-authorized persons.

. . . to ask questions about the research at any time before, during and after participation in this research. Every effort will be made to answer your questions honestly and to your complete satisfaction.

. . . to maintain all your rights and privileges as a citizen. No waiving of any legal rights is implied or intended by your participation in research.

**IF YOU HAVE ANY QUESTIONS CONCERNING YOUR RIGHTS,
CONTACT THE INSTITUTIONAL REVIEW BOARD
TELEPHONE (402) 559-6463**

Reference:

DEMOGRAPHIC INFORMATION

YOUR PERSONAL INFORMATION:

Gender ☐ Male ☐ Female

Birthdate: _____

City/State of Residence _____

City/State of SIDS Alliance or SIDS Network where you are a member:

SIDS INFORMATION:

What year was your infant born: _____

What year did he/she die of SIDS: _____

OPTIONAL INFORMATION

Marital Status ☐ Single ☐ Married ☐ Divorced

Race/Ethnicity ☐ Afro-American ☐ Asian ☐ Caucasian ☐ Hispanic

☐ Native American ☐ Pacific Islander ☐ Other

Highest Level of Education: ☐ some high school/GED ☐ some college/ Associates Degree

☐ Bachelor's Degree ☐ Master's or Doctorate Degree

Do you have other children besides the infant that died of SIDS? (Yes/No) _____

What is the birth order of the infant that died of SIDS? (firstborn, second born etc.):

Appendix C

NEO-FFI Factor Inventory

(NEO-FFI)

NEO

Five-Factor Inventory

Form S

Paul T. Costa, Jr., Ph.D., and Robert R. McCrae, Ph.D.

Instructions

Write only where indicated in this booklet. Carefully read all of the instructions before beginning. This questionnaire contains 60 statements. Read each statement carefully. For each statement fill in the circle with the response that best represents your opinion. Make sure that your answer is in the correct box.

Fill in (SD) if you *strongly disagree* or the statement is definitely false.

Fill in (D) if you *disagree* or the statement is mostly false.

Fill in (N) if you are *neutral* on the statement, you cannot decide, or the statement is about equally true and false.

Fill in (A) if you *agree* or the statement is mostly true.

Fill in (SA) if you *strongly agree* or the statement is definitely true.

For example, if you *strongly disagree* or believe that a statement is definitely false, you would fill in the (SD) for that statement.

Example



Fill in only one response for each statement. Respond to all of the statements, making sure that you fill in the correct response. **DO NOT ERASE!** If you need to change an answer, make an "X" through the incorrect response and then fill in the correct response.

Note that the responses are numbered in *rows*. Before responding to the statements, turn to the inside of the booklet and enter your name, age, and sex and the date.

PAR Psychological Assessment Resources, Inc./P.O. Box 998/Odessa, FL 33556/Toll-Free 1-800-331-TEST

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Name _____ Age _____ Sex _____ Date _____

1. I am not a worrier.
2. I like to have a lot of people around me.
3. I don't like to waste my time daydreaming.
4. I try to be courteous to everyone I meet.
5. I keep my belongings neat and clean.
6. I often feel inferior to others.
7. I laugh easily.
8. Once I find the right way to do something, I stick to it.
9. I often get into arguments with my family and co-workers.
10. I'm pretty good about pacing myself so as to get things done on time.
11. When I'm under a great deal of stress, sometimes I feel like I'm going to pieces.
12. I don't consider myself especially "light-hearted."
13. I am intrigued by the patterns I find in art and nature.
14. Some people think I'm selfish and egotistical.
15. I am not a very methodical person.
16. I rarely feel lonely or blue.
17. I really enjoy talking to people.
18. I believe letting students hear controversial speakers can only confuse and mislead them.
19. I would rather cooperate with others than compete with them.
20. I try to perform all the tasks assigned to me conscientiously.
21. I often feel tense and jittery.
22. I like to be where the action is.
23. Poetry has little or no effect on me.
24. I tend to be cynical and skeptical of others' intentions.
25. I have a clear set of goals and work toward them in an orderly fashion.
26. Sometimes I feel completely worthless.
27. I usually prefer to do things alone.
28. I often try new and foreign foods.
29. I believe that most people will take advantage of you if you let them.
30. I waste a lot of time before settling down to work.
31. I rarely feel fearful or anxious.
32. I often feel as if I'm bursting with energy.
33. I seldom notice the moods or feelings that different environments produce.
34. Most people I know like me.
35. I work hard to accomplish my goals.
36. I often get angry at the way people treat me.
37. I am a cheerful, high-spirited person.
38. I believe we should look to our religious authorities for decisions on moral issues.
39. Some people think of me as cold and calculating.
40. When I make a commitment, I can always be counted on to follow through.

41. Too often, when things go wrong, I get discouraged and feel like giving up.
42. I am not a cheerful optimist.
43. Sometimes when I am reading poetry or looking at a work of art, I feel a chill or wave of excitement.
44. I'm hard-headed and tough-minded in my attitudes.
45. Sometimes I'm not as dependable or reliable as I should be.
46. I am seldom sad or depressed.
47. My life is fast-paced.
48. I have little interest in speculating on the nature of the universe or the human condition.
49. I generally try to be thoughtful and considerate.
50. I am a productive person who always gets the job done.
51. I often feel helpless and want someone else to solve my problems.
52. I am a very active person.
53. I have a lot of intellectual curiosity.
54. If I don't like people, I let them know it.
55. I never seem to be able to get organized.
56. At times I have been so ashamed I just wanted to hide.
57. I would rather go my own way than be a leader of others.
58. I often enjoy playing with theories or abstract ideas.
59. If necessary, I am willing to manipulate people to get what I want.
60. I strive for excellence in everything I do.

Enter your responses here—remember to enter responses across the rows.

SD = Strongly Disagree; D = Disagree; N = Neutral; A = Agree; SA = Strongly Agree

1 (SD) (D) (N) (A) (SA)	2 (SD) (D) (N) (A) (SA)	3 (SD) (D) (N) (A) (SA)	4 (SD) (D) (N) (A) (SA)	5 (SD) (D) (N) (A) (SA)
6 (SD) (D) (N) (A) (SA)	7 (SD) (D) (N) (A) (SA)	8 (SD) (D) (N) (A) (SA)	9 (SD) (D) (N) (A) (SA)	10 (SD) (D) (N) (A) (SA)
11 (SD) (D) (N) (A) (SA)	12 (SD) (D) (N) (A) (SA)	13 (SD) (D) (N) (A) (SA)	14 (SD) (D) (N) (A) (SA)	15 (SD) (D) (N) (A) (SA)
16 (SD) (D) (N) (A) (SA)	17 (SD) (D) (N) (A) (SA)	18 (SD) (D) (N) (A) (SA)	19 (SD) (D) (N) (A) (SA)	20 (SD) (D) (N) (A) (SA)
21 (SD) (D) (N) (A) (SA)	22 (SD) (D) (N) (A) (SA)	23 (SD) (D) (N) (A) (SA)	24 (SD) (D) (N) (A) (SA)	25 (SD) (D) (N) (A) (SA)
26 (SD) (D) (N) (A) (SA)	27 (SD) (D) (N) (A) (SA)	28 (SD) (D) (N) (A) (SA)	29 (SD) (D) (N) (A) (SA)	30 (SD) (D) (N) (A) (SA)
31 (SD) (D) (N) (A) (SA)	32 (SD) (D) (N) (A) (SA)	33 (SD) (D) (N) (A) (SA)	34 (SD) (D) (N) (A) (SA)	35 (SD) (D) (N) (A) (SA)
36 (SD) (D) (N) (A) (SA)	37 (SD) (D) (N) (A) (SA)	38 (SD) (D) (N) (A) (SA)	39 (SD) (D) (N) (A) (SA)	40 (SD) (D) (N) (A) (SA)
41 (SD) (D) (N) (A) (SA)	42 (SD) (D) (N) (A) (SA)	43 (SD) (D) (N) (A) (SA)	44 (SD) (D) (N) (A) (SA)	45 (SD) (D) (N) (A) (SA)
46 (SD) (D) (N) (A) (SA)	47 (SD) (D) (N) (A) (SA)	48 (SD) (D) (N) (A) (SA)	49 (SD) (D) (N) (A) (SA)	50 (SD) (D) (N) (A) (SA)
51 (SD) (D) (N) (A) (SA)	52 (SD) (D) (N) (A) (SA)	53 (SD) (D) (N) (A) (SA)	54 (SD) (D) (N) (A) (SA)	55 (SD) (D) (N) (A) (SA)
56 (SD) (D) (N) (A) (SA)	57 (SD) (D) (N) (A) (SA)	58 (SD) (D) (N) (A) (SA)	59 (SD) (D) (N) (A) (SA)	60 (SD) (D) (N) (A) (SA)

Have you responded to all of the statements? _____ Yes _____ No

Have you entered your responses in the correct boxes? _____ Yes _____ No

Have you responded accurately and honestly? _____ Yes _____ No

Appendix D

Perinatal Grief Scale

(PGS)

PERINATAL GRIEF SCALE

33 Item Short Version

Lori J. Toedter, Ph.D.
Moravian College

and

Judith N. Lasker, Ph.D.
Lehigh University

SCORING INSTRUCTIONS

The total PGS score is arrived at by first reversing all of the items EXCEPT 11 AND 33. By reversing the items, higher scores now reflect more intense grief.

Then add the scores together. The result is a total scale consisting of 33 items with a possible range of 33-165.

The three subscales consist of the sum of the scores of 11 items each, with a possible range of 11-55.

Subscale 1

Active Grief

1
3
5
6
7
10
12
13
14
19
27

Subscale 2

Difficulty Coping

2
4
8
* 11
21
24
25
26
28
30
* 33

Subscale 3

Despair

9
15
16
17
18
20
22
23
29
31
32

* Do not reverse.

PERINATAL GRIEF SCALE

PRESENT THOUGHTS AND FEELINGS ABOUT YOUR LOSS

Each of the items is a statement of thoughts, and feelings which some people have concerning a loss such as yours. There are no right or wrong responses to these statements. For each item, circle the number which best indicates the extent to which you agree or disagree with it at the present time. If you are not certain, use the "neither" category. Please try to use this category only when you truly have no opinion.

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
1. I feel depressed.	1	2	3	4	5
2. I find it hard to get along with certain people	1	2	3	4	5
3. I feel empty inside	1	2	3	4	5
4. I can't keep up with my normal activities.	1	2	3	4	5
5. I feel a need to talk about the baby.	1	2	3	4	5
6. I am grieving for the baby.	1	2	3	4	5
7. I am frightened.	1	2	3	4	5
8. I have considered suicide since the loss.	1	2	3	4	5
9. I take medicine for my nerves.	1	2	3	4	5
10. I very much miss the baby.	1	2	3	4	5
11. I feel I have adjusted well to the loss.	1	2	3	4	5
12. It is painful to recall memories of the loss.	1	2	3	4	5
13. I get upset when I think about the baby.	1	2	3	4	5
14. I cry when I think about him/her	1	2	3	4	5
15. I feel guilty when I think about the baby	1	2	3	4	5
16. I feel physically ill when I think about the baby.	1	2	3	4	5

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
17. I feel unprotected in a dangerous world since he/she died	1	2	3	4	5
18. I try to laugh, but nothing seems funny anymore.	1	2	3	4	5
19. Time passes so slowly since the baby died.	1	2	3	4	5
20. The best part of me died with the baby.	1	2	3	4	5
21. I have let people down since the baby died.	1	2	3	4	5
22. I feel worthless since he/she died.	1	2	3	4	5
23. I blame myself for the baby's death.	1	2	3	4	5
24. I get cross at my friends and relatives more than I should.	1	2	3	4	5
25. Sometimes I feel like I need a professional counselor to help me get my life back together again.	1	2	3	4	5
26. I feel as though I'm just existing and not really living since he/she died.	1	2	3	4	5
27. I feel so lonely since he/she died.	1	2	3	4	5
28. I feel somewhat apart and remote, even among friends.	1	2	3	4	5
29. It's safer not to love	1	2	3	4	5
30. I find it difficult to make decisions since the baby died.	1	2	3	4	5
31. I worry about what my future will be like	1	2	3	4	5
32. Being a bereaved parent means being a "Second-Class Citizen".	1	2	3	4	5
33. It feels great to be alive.	1	2	3	4	5